

Illinois Department of Public Health  
Lysosomal Storage Disorders Subcommittee  
Illinois Department of Public Health  
Meeting and Conference Call Minutes: December 19, 2013

Subcommittee Members Attending:

Barbara Burton-Lurie Children's Hospital – Chair  
Zohra Shad- University of Illinois at Chicago Hospital  
Darrel Waggoner- University of Chicago  
Lainie Friedman Ross – University of Chicago  
Amy Knight Johnson – University of Chicago

IDPH Staff:

George Dizikes, Khaja Basheeruddin, Rong Shao, Claudia Nash, Jean Becker, Linda Robinson, Nitika Sharma

Background

The meeting was called to order at 2:00 PM.

IDPH Laboratory Status Report

Dr. Basheeruddin reported that all four testing instruments are installed and working properly for the six-plex assay (Krabbe, Pompe, Gaucher, Fabry, Niemann-Pick and MPS I). The lab is gathering data to determine cutoffs, which should be completed in February or March 2014. In April, tandem testing with Perkin Elmer will occur and a pilot test period will then begin with newborn screening specimens being tested from 1-2 hospitals. By July 2014 statewide testing will be implemented.

In the interim, necessary changes to the newborn screening Perkin Elmer database are being made. Hospitals will be notified about the implementation of testing and the changes in reporting early in 2014. Information will also be provided to the Illinois Chapter of the American Academy of Pediatrics about the initiation of screening.

Review of Newborn Screening Results

The data collection tools used by Missouri were reviewed and it was determined that in Illinois a standard spreadsheet with the same data elements should be created for each disorder. It was also decided that each center could track their own cases and on a monthly basis submit their spreadsheet to IDPH with the patient names removed, so that data from all centers can be shared and reviewed with the entire LSD subcommittee.

Next Steps

Jean Becker at IDPH will prepare draft spreadsheets for each disorder which will be emailed to the LSD subcommittee for final review. The group decided to not meet in January, and set February 27 at 2 pm for the next meeting date.